



**NKDEP**

National Kidney Disease  
Education Program

# **Chronic Kidney Disease Compendium**

*Directory of  
Kidney-Related Organizations*

**Section 2**

## Introduction

This section of the *Chronic Kidney Disease Compendium* lists professional and voluntary organizations that have a mission relevant and important to the care and/or prevention of chronic kidney disease. The focus of the *Compendium* is pre-end-stage renal disease (ESRD); however, this section includes some organizations that deal mainly with ESRD issues such as dialysis and transplantation. The National Kidney Disease Education Program's (NKDEP) chronic kidney disease projects may include outreach to these groups, and their resources may be useful in other ways. Organizations are listed in alphabetical order.

The *Compendium* in its current form represents NKDEP's best effort to list available resources on chronic kidney disease; however the document is not exhaustive or comprehensive. Submission of appropriate entries is highly encouraged. Reference to the organizations, programs, and materials in this document are for informational purposes only and does not constitute or imply NKDEP's endorsement or guarantee of medical accuracy or completeness. Submissions should be sent via the comment section on the website <http://www.nkdep.nih.gov/contact.htm> or by mail to:

### NKDEP

3 Kidney Information Way  
Bethesda, MD 20892-3575

The following index will assist you in finding kidney-related organizations. Page numbers are provided for your convenience. You can use the "go to" page command in Adobe Acrobat to locate the item of your choice. For Mac users, press the Apple Key and N key together. For PC users, press the CTRL key and N key together.

## Index List of Organizations

American Academy of Nephrology Physician Assistants **2**  
American Association of Kidney Patients **3**  
American Dietetic Association **3**  
American Kidney Fund **3**  
American Nephrology Nurses' Association **4**  
American Society for Artificial Internal Organs **4**  
American Society of Nephrology **4**  
American Society of Pediatric Nephrology **5**  
American Society of Transplantation **5**  
American Society of Transplant Surgeons **5**  
Council of American Kidney Societies **6**  
Council on the Kidney in Cardiovascular Disease (American Heart Association) **6**  
Division of Kidney, Urologic, and Hematologic Diseases **6**  
Division of Nutrition Research Coordination **7**

Forum of End-Stage Renal Disease Networks 7  
 IgA Nephropathy Foundation 8  
 IgA Nephropathy Support Network 8  
 International Pediatric Nephrology Association 8  
 International Society for Peritoneal Dialysis 9  
 International Society of Nephrology 9  
 International Society of Renal Nutrition and Metabolism 9  
 International Transplant Nurses Society 9  
 Kidney Cancer Association 10  
 Kidney Foundation of Greater Cincinnati 10  
 Kidney Transplant/Dialysis Association, Inc. 10  
 LifeBanc, Inc. 11  
 Life Options Rehabilitation Program 11  
 Minneapolis Medical Research Foundation 12  
 Minority Organ and Tissue Transplant Educational Program 12  
 National Association of Nephrology Technicians/Technologists 13  
 National Diabetes Education Program 13  
 National Diabetes Information Clearinghouse 13  
 National Foundation for Transplants (formerly Organ Transplant Fund) 14  
 National High Blood Pressure Education Program 14  
 National Hypertension Association, Inc. 15  
 National Institute of Diabetes and Digestive and Kidney Diseases 15  
 National Kidney and Urologic Diseases Information Clearinghouse 16  
 National Kidney Disease Education Program 16  
 National Kidney Foundation 16  
 NephCure Foundation 17  
 Nephrogenic Diabetes Insipidus Foundation 17  
 Nephrology Analytical Services 17  
 North American Society for Dialysis and Transplantation 18  
 North American Transplant Coordinators Organization 18  
 Office of Minority Health Research Coordination 18  
 Oxalosis and Hyperoxaluria Foundation 19  
 Polycystic Kidney Disease Foundation 19  
 Renal Physicians Association 20  
 Transplant Recipients International Organization 20  
 The Transplantation Society 21  
 United Network for Organ Sharing 21  
 United States Renal Data System 21

### **American Academy of Nephrology Physician Assistants**

Email: [blaine@aanpa.org](mailto:blaine@aanpa.org) or [info@aanpa.org](mailto:info@aanpa.org)

Website: <http://aanpa.org>

**Mission:** To support the professional growth, development, training, education, and networking of physician assistants within the specialty practice of nephrology.

### **American Association of Kidney Patients**

3505 East Frontage Road, Suite 315  
Tampa, FL 33607  
Phone: (800) 749-2257 or (813) 636-8100  
Fax: (813) 636-8122  
Email: [info@aakp.org](mailto:info@aakp.org)  
Website: <http://www.aakp.org>  
Kris Robinson, Executive Director

**Mission:** To serve the needs and interests of kidney patients and their families. Founded by kidney patients to help others with kidney failure cope with its physical and emotional impact on their lives.

**Materials:** Renalife (quarterly journal) and The Renal Flash (monthly electronic newsletter).

**Local Groups:** 17

### **American Dietetic Association**

216 West Jackson Boulevard  
Chicago, IL 60606-6995  
Phone: (800) 877-1600 or (312) 899-0040  
Website: <http://www.eatright.org>  
Susan T. Borra, RD, President

**Mission:** To promote optimal nutrition and well-being for all people by advocating for its members. The American Dietetic Association is the nation's largest organization of food and nutrition professionals.

**Materials:** Journal of the American Dietetic Association. Professional and consumer information materials.

**Local Groups:** 53.

### **American Kidney Fund (AKF)**

6110 Executive Boulevard, Suite 1010  
Rockville, MD 20852  
Phone: (800) 638-8299 or (301) 881-3052  
Fax: (301) 881-0898  
Email: [helpline@akfinc.org](mailto:helpline@akfinc.org)  
Website: <http://akfinc.org>  
Karen Sendelback, CFRE, Executive Director

**Mission:** To provide direct financial assistance, comprehensive educational programs, research grants, and community-service projects for the benefit of kidney patients.

**Materials:** AKF Advocate, Clinical Strategies: The AKF Newsletter for Nephrology Professionals, and patient and public education brochures.

### **American Nephrology Nurses' Association (ANNA)**

East Holly Avenue, Box 56  
Pittman, NJ 08071-0056  
Phone: (888) 600-2662 or (856) 256-2320  
Fax: (856) 589-7463  
Email : [anna@ajn.com](mailto:anna@ajn.com)  
Website: <http://anna.inurse.com>  
Mary Ann Gould, MSN, RN, CNN, President

**Mission:** To advance the professional development of registered nurses practicing in nephrology, transplantation, and related therapies, and to promote the highest standards of patient care.

**Materials:** Nephrology Nursing Journal, ANNA Update (bimonthly newsletter), Core Curriculum for Nephrology Nursing, position statements, and clinical monographs.

**Local Groups:** 4 regions, 100 chapters.

### **American Society for Artificial Internal Organs**

National Office  
P.O. Box C  
Boca Raton, FL 33429-0468  
Phone: (561) 391-8589  
Fax: (561) 368-9153  
Email: [info@asaio.com](mailto:info@asaio.com)  
Website: <http://www.asaio.com>  
Karen Burke, Executive Director

**Mission:** The American Society for Artificial Internal Organs, Inc. (ASAIO) promotes the development, application, and awareness of organ technologies that enhance quality and duration of life.

**Materials:** ASAIO Journal (bimonthly peer-reviewed journal), ASAIO Abstracts (for annual conference), ASAIO Newsletter (quarterly newsletter on public policy education project).

### **American Society of Nephrology**

2025 M Street, N.W., Suite 800  
Washington, DC 20036  
Phone: (202) 367-1190  
Fax: (202) 367-2190  
Email: [asn@dc.sba.com](mailto:asn@dc.sba.com)  
Website: <http://www.asn-online.org>  
Karen Campbell, PhD, Executive Director

**Mission:** To advance the knowledge and practice of nephrology.

**Materials:** Journal of the American Society of Nephrology (JASN) and Highlights (member newsletter).

### **American Society of Pediatric Nephrology**

c/o James Whitcomb Riley Hospital for Children  
Wells Research Center, Room 2600A  
702 Barnhill Drive  
Indianapolis, IN 46202  
Phone: (317) 278-0854  
Email: [kmatteso@iupui.edu](mailto:kmatteso@iupui.edu)  
Website: <http://www.aspneph.com>  
Aaron L. Friedman, MD, President

**Mission:** To promote public and professional educational programs in pediatric nephrology.

**Materials:** Kidney Notes (bimonthly newsletter).

### **American Society of Transplantation (AST)**

17000 Commerce Parkway, Suite C  
Mt. Laurel, NJ 08054  
Phone: (856) 439-9986  
Fax: (856) 439-9982  
Email: [ast@ahint.com](mailto:ast@ahint.com)  
Website: <http://www.a-s-t.org>  
Susan Nelson, Executive Director

**Mission:** To promote and encourage education and research with respect to transplantation medicine and immunology. To provide a forum for the exchange of scientific information related to transplantation medicine and immunology. To give physicians and allied scientists interested in transplantation medicine and immunology an effective, unified, and authoritative voice in dealing with other government, medical, and private agencies and organizations.

**Materials:** AST Newsletter (member newsletter), AST Primer on Transplantation, American Journal of Transplantation.

### **American Society of Transplant Surgeons**

1020 North Fairfax Street, Suite 200  
Alexandria, VA 22314  
Phone: (888) 990-2787 or (703) 684-5990  
Fax: (703) 684-6303  
Email: [gaildurant@earthlink.net](mailto:gaildurant@earthlink.net)  
Website: <http://www.ast.org>  
Gail D. Durant, Executive Director

**Mission:** To promote and encourage education and research with respect to organ and tissue transplantation so as to facilitate progress in the saving of lives and/or enhancing the quality of lives of patients afflicted with end-stage organ failure. To collaborate with existing public and private organizations to promote and encourage education and research in transplantation, and to participate and assist in the coordination of efforts or formulation of programs by all surgeons,

physicians, scientists, agencies, and health personnel, which will provide maximal efficiency and optimal benefit to recipients of transplants.

**Materials:** American Journal of Transplantation.

### **Council of American Kidney Societies (CAKS)**

1444 I Street, N.W., Suite 700

Washington, DC 20005

Phone: (202) 712-9031

Fax: (202) 216-9646

Email: [caks@bostromdc.com](mailto:caks@bostromdc.com)

Derrick Latos, MD, President

**Mission:** To serve as a representative body of scientific and professional nephrology practice organizations engaged in the promotion and support of clinical and basic research and medical practice in the broad fields of adult and pediatric kidney diseases.

### **Council on the Kidney in Cardiovascular Disease (American Heart Association)**

Tulane University Medical Center

Medical Department SL 12

1430 Tulane Avenue

New Orleans, LA 70112-2699

Phone: (504) 582-7801

Fax: (504) 584-1600

Email: [jpusche@tulane.edu](mailto:jpusche@tulane.edu)

Website: <http://216.185.112.5/presenter.jhtml?identifier=1121>

Dr. Jules B. Puschett, Chairperson

**Mission:** To reduce cardiovascular-related death and disability through research, communication, advocacy, and education about the kidney. A new strategic plan for accomplishing this goal is under development.

### **Division of Kidney, Urologic, and Hematologic Diseases (KUH)**

National Institute of Diabetes and Digestive and Kidney Diseases

National Institutes of Health

2 Democracy Plaza

6707 Democracy Boulevard, Room 654, MSC 5458

Bethesda, MD 20892-5458

Phone: 301-594-7717

Fax: 301-480-3510

Website: <http://www.niddk.nih.gov/fund/divisions/KUH/KUHintro.htm>

Dr. Josephine Briggs, Director

**Mission:** The National Institutes of Health (NIH) Division of Kidney, Urologic, and Hematologic Diseases (KUH) within the National Institute of Diabetes and Digestive and Kidney Diseases provides research funding and support for basic and clinical research in the areas of kidney diseases including end-stage renal disease, kidney disease of diabetes, IgA nephropathy, hemolytic uremic syndrome, polycystic kidney disease, hypertensive nephrosclerosis, acute renal failure and fluid and electrolyte disorders; urinary tract diseases including benign prostatic hyperplasia, urinary tract infections, kidney stones, impotence, urinary incontinence, and interstitial cystitis; and disorders of the blood and blood-forming organs.

**Materials:** See the National Kidney and Urologic Diseases Information Clearinghouse.

### **Division of Nutrition Research Coordination**

National Institute of Diabetes and Digestive and Kidney Diseases

National Institutes of Health

6707 Democracy Boulevard, Room 679, MSC 5461

Bethesda, MD 20892-5450

Phone: (301) 594-8822

Fax: (301) 480-3768

Website: <http://dnrc.nih.gov>

Dr. Van S. Hubbard, Director

**Mission:** The National Institutes of Health (NIH) Division of Nutrition Research Coordination (DNRC) located within the National Institute of Diabetes and Digestive and Kidney Diseases advises the NIH Director and others on nutritional research issues, and works with the NIH organizational components to coordinate nutrition research and training initiatives. Located within the DNRC is the NIH Nutrition Coordinating Committee that operates as an NIH-wide forum and locus for the coordination of nutrition activities, helping the NIH to avoid duplication of effort. Nutrition research supported by the NIH includes studies on the effects of nutrients on human growth and development, health maintenance and promotion, disease prevention, and disease treatment. Services to consumers include publication and reference information. Some materials are available in Spanish, and the organization publishes a newsletter and catalog. It also sponsors conferences and training seminars.

### **Forum of End-Stage Renal Disease Networks**

1527 Huguenot Road

Midlothian, VA 23113

Phone: (804) 794-2586

Fax: (804) 378-7351

Email: [forum@forum.esrd.net](mailto:forum@forum.esrd.net)

Website: <http://www.esrdnetworks.org>

Dr. Alan S. Kliger, MD, Board President

Janet D. Crow, Administrator

Bonnie Freshly, Project Coordinator

**Mission:** The mission of the Forum is to support and advocate on behalf of the End-Stage Renal Disease Networks in promoting methods to improve the quality of care to patients with renal disease. The Forum aspires to provide leadership in the renal community through education, data management, dissemination of information and quality improvement, and to promote collaboration within our profession.

### **IgA Nephropathy Foundation**

One Johnson Pier, Suite 36  
Half Moon Bay, CA 94306  
Email: [info@igan.org](mailto:info@igan.org)  
Website: <http://www.igan.org>

**Mission:** To provide vital and up-to-date information on the diagnosis and treatment of IgA nephropathy to patients, their families, and their health care providers.

### **IgA Nephropathy Support Network**

9 G Street, #B  
Turners Falls, MA 01376  
Email: [igan@gis.net](mailto:igan@gis.net)  
Dale M. Hellegers, President

**Mission:** To assist patients with IgA nephropathy and their families; to serve as a clearinghouse for dissemination of information about IgA nephropathy; and to promote research for a possible cure.

**Materials:** Newsletter and pamphlets.

### **International Pediatric Nephrology Association**

c/o Montefiore Medical Center  
111 East 210th Street  
Bronx, NY 10467  
Phone: (718) 665-1120  
Fax: (718) 652-3136  
Ira Greifer, MD, Secretary General

**Mission:** To promote professional education and improve health care for children with kidney and urologic diseases.

**Materials:** Pediatric Nephrology.

### **International Society for Peritoneal Dialysis**

c/o Sarah Prichard, MD  
Royal Victoria Hospital  
687 Pine Avenue West  
Montreal, PQ H3A 1A1  
CANADA  
Website: <http://www.ispd.org>  
Sarah Prichard, MD, President

**Mission:** To advance knowledge of peritoneal dialysis (PD).

**Materials:** Peritoneal Dialysis International, PD News, PD Today, Advances in Peritoneal Dialysis.

### **International Society of Nephrology**

Emory University Renal Division  
1639 Pierce Drive, WMB 338  
Atlanta, GA 30322  
Phone: (404) 727-8527  
Fax: (404) 727-3425  
Email: [mtmurra@emory.edu](mailto:mtmurra@emory.edu)  
Website: <http://www.isn-online.org>  
William E. Mitch, MD, Treasurer  
Robert C. Atkins, MD, President

**Mission:** To educate nephrologists about research and patient care.

**Materials:** Kidney International.

### **International Society of Renal Nutrition and Metabolism**

Division of Nephrology, TB 136  
University of California, Davis  
Davis, CA 95616  
Website: <http://wdsroot.ucdavis.edu/clients/renalsoc/default.html>  
George A. Kaysen, MD, PhD, President

**Mission:** To advance the knowledge of nutrition and metabolism in renal disease and renal failure, and to foster communication of the advancements of this knowledge by means of scientific meetings and cooperation with other scientific societies of nephrology, nutrition, biochemistry, and physiology.

**Materials:** Newsletter.

### **International Transplant Nurses Society (ITNS)**

1739 East Carson Street, Box 351  
Pittsburgh, PA 15203-1700

Phone: (412) 488-0240  
Fax: (412) 431-5911  
Email: [itns@msn.com](mailto:itns@msn.com)  
Website: <http://www.itns.org>

**Mission:** Professional membership organization of transplant nurses dedicated to improving patient care through dissemination of information and symposia.

**Materials:** ITNS Newsletter, Progress in Transplantation (journal).

**Local Groups:** 19.

### **Kidney Cancer Association**

1235 Sherman Avenue, Suite 203  
Evanston, IL 60202-1378  
Phone: (800) 850-9132 or (847) 332-1051  
Fax: (847) 332-2978  
Email: [office@kidneycancerassociation.org](mailto:office@kidneycancerassociation.org)  
Website: <http://kidneycancerassociation.org>  
Carl F. Dixon, Executive Director and President

**Mission:** To provide information to patients and physicians; to sponsor research on kidney cancer; and to act as an advocate on behalf of patients with the Federal Government, insurance companies, and employers.

**Materials:** Kidney Cancer (56-page booklet for patients), Kidney Cancer News (quarterly newsletter), and public policy papers.

**Local Groups:** in 24 major cities including New York, Los Angeles, and Chicago.

### **Kidney Foundation of Greater Cincinnati**

220 Victory Parkway, Suite 510  
Cincinnati, OH 45206  
Phone: (513) 961-8105  
Fax: (513) 961-8120  
Email: [kidney@kidney.cincinnati.org](mailto:kidney@kidney.cincinnati.org)  
Website: <http://home.fuse.net/kidney/programs.htm> or <http://www.kidneycincinnati.org>  
Leslie Ostrander, Executive Director

**Mission:** To provide assistance to area kidney patients in need while offering professional and community education programs and grants for local kidney and kidney-related research.

### **Kidney Transplant/Dialysis Association, Inc.**

P.O. Box 51362 GMF  
Boston, MA 02205-1362  
Phone: (781) 641-4000  
Email: [ktda@ma.ultranet.com](mailto:ktda@ma.ultranet.com)  
Website: <http://www.ktda.org>

**Mission:** To provide financial aid, information, and emotional support to chronic renal disease patients and their families. The Kidney Transplant/Dialysis Association, Inc. (KT/DA) is an organization made up of artificial kidney and kidney transplant patients, their families and friends, and health professionals. Our officers are themselves kidney patients or spouses of kidney patients.

**Materials:** RenalGram (quarterly newsletter); KT/DA Patient Handbook (available online).

### **LifeBanc, Inc.**

20600 Chagrin Boulevard, Suite 350

Cleveland, OH 44122-5343

Phone: (888) 558-5433 or (216) 752-5433

Fax: (216) 751-4204

Email: [info@lifebanc.org](mailto:info@lifebanc.org)

Website: <http://www.lifebanc.org>

**Mission:** LifeBanc is a federally approved non-profit organ procurement organization established to assist with the identification, management, procurement, and subsequent utilization of organs and tissue for transplantation, and is certified by the Center for Medicare & Medicaid Services (formerly the Health Care Finance Administration) to coordinate donations in Northeast Ohio. LifeBanc requires input and assistance from administrative, medical, nursing, and paramedical personnel in the hospital as well as community support.

### **Life Options Rehabilitation Program**

c/o Medical Education Institute

414 D'Onofrio Drive, Suite 200

Madison, WI 53719

Phone: (800) 468-7777 or (608) 833-8033

Fax: (608) 833-8366

Email: [Lifoptions@MEIresearch.org](mailto:Lifoptions@MEIresearch.org)

Website: <http://www.lifeoptions.org>

Dori Schatell, Executive Director

**Mission:** Life Options is dedicated to helping people live long and live well with kidney disease. A program of qualitative and quantitative research and free, research-based educational materials, Life Options is guided by a multidisciplinary advisory council of patients, physicians, nurses, social workers, dietitians, administrators, physical therapists, network directors, and industry representatives. Life Options partners with other organizations and providers to share ideas and messages and offers free technical support. Life Options is administered by the non-profit Medical Education Institute (MEI), which serves the mission of helping people with chronic diseases learn to manage and improve their health, and is supported by Amgen Renal Advances.

### **Minneapolis Medical Research Foundation**

914 South Eighth Street  
Minneapolis, MN 55404-1204  
Phone: (612) 347-5099  
Fax: (612) 337-7189  
Email: [mmacres@mmrfweb.org](mailto:mmacres@mmrfweb.org)  
Website: <http://www.mmrfweb.org>  
Michael West, MD, President

**Mission:** The Minneapolis Medical Research Foundation (MMRF) oversees the research at Hennepin County Medical Center. The mission of MMRF is to improve patient care and the health of the community through research and education. MMRF has active research programs in alternative medicine; cancer; clinical outcomes; chronic fatigue syndrome; children's growth and nutrition; diabetes and metabolism; heart disease; liver disease; nutraceuticals; organ transplantation; pediatric asthma; sleep disorders; smoking prevention; women's health; and trauma. The Foundation is partially sponsored by the National Institutes of Health. The areas of interests are organ transplantation (kidney and lung), dialysis, hyperbaric medicine, audiovisual training programs, endocrine research, program evaluation methods and outcomes research, actions of drugs (clinical evaluation), transplant immunology, addiction, AIDS, Alzheimer's disease, trauma, health care policy, and alternative medicine. The staff answers inquiries, provides advisory and consulting services, and evaluates data.

### **Minority Organ and Tissue Transplant Educational Program**

2041 Georgia Avenue, N.W.  
Ambulatory Care Center, Suite 3100  
Washington, DC 20060  
Phone: (800) 393-2839 or (202) 865-4888  
Fax: (202) 865-4880  
Email: [pmiles@nationalmottep.org](mailto:pmiles@nationalmottep.org)  
Website: <http://www.nationalmottep.org>  
Patrice Miles, Executive Director

**Mission:** The Minority Organ and Tissue Transplant Educational Program (MOTTEP) was established in 1995 and is sponsored by the National Institute of Diabetes and Digestive and Kidney Diseases and the National Center on Minority Health Disparities (formerly the Office of Minority Health). Its goals are to encourage healthier lifestyles to prevent kidney diseases and kidney failure, and to increase organ and tissue donation among racial and ethnic minorities. Since its inception, MOTTEP has contributed to the observed national trends of increased minority organ and tissue donation, an important advancement since African Americans, who make up 12.6 percent of the general population but 29.8 percent of patients with end-stage renal disease, are less likely to receive needed transplants.

**Local Groups:** 14.

## **National Association of Nephrology Technicians/Technologists**

P.O. Box 2307

Dayton, OH 45401-2307

Phone: (877) 607-6268 or (937) 586-3705

Fax: (937) 586-3699

Email: [nant@nant.meinet.com](mailto:nant@nant.meinet.com)

Website: <http://www.dialysistech.org>

Francine W. Rickenbach, CAE, Executive Director

**Mission:** Promote the highest quality of care for end-stage renal disease (ESRD) patients through education and professionalism by providing educational opportunities for the technical practitioner and other members of the integrated care team, representing the technical professional in the regulatory and legislative arena, developing technical professionals in leadership roles, achieving recognition for the role and significant contribution of the technical practitioner to the total care of the ESRD patient, and serving as a resource for the ESRD community to accomplish each of these goals.

**Materials:** Bimonthly newsletter, educational and technical manuals, regional educational meetings.

**Local Groups:** 31.

## **National Diabetes Education Program**

Website: <http://www.ndep.nih.gov> or <http://www.cdc.gov/diabetes/projects/index.htm>

**Mission:** To improve the treatment and outcomes for people with diabetes, to promote early diagnosis, and to prevent the onset of type 2 diabetes. The National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) of the National Institutes of Health (NIH) and the Division of Diabetes Translation of the Centers for Disease Control and Prevention (CDC) jointly sponsor the program with the participation of over 200 partner organizations.

**Materials:** Program Update Newsletter, various materials for people with diabetes (in English and Spanish), materials for health professionals (in English and Spanish), materials for organizations, and media kits.

## **National Diabetes Information Clearinghouse**

1 Information Way

Bethesda, MD 20892-3560

Phone: (800) 860-8747 or (301) 654-3327

Fax: (301) 907-8906

Email: [ndic@info.niddk.nih.gov](mailto:ndic@info.niddk.nih.gov)

Website: <http://www.niddk.nih.gov/health/diabetes/ndic.htm>

**Mission:** The National Diabetes Information Clearinghouse (NDIC) is an information dissemination service of the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK). NIDDK is part of the National Institutes of Health, one of eight health agencies of the Public Health Service, which is under the U.S. Department of Health and Human Services.

NDIC was established in 1978 to increase knowledge and understanding about diabetes among patients, health care professionals, and the general public. To carry out this mission, NDIC works closely with NIDDK's Diabetes Research and Training Centers; the National Diabetes Education Program; professional, patient, and voluntary associations; Government agencies; and State health departments to identify and respond to informational needs about diabetes and its management.

**Materials:** Publications on diabetes at various reading levels and for various audiences.

**National Foundation for Transplants (NFT)  
(formerly the Organ Transplant Fund)**

1102 Brookfield Road, Suite 200

Memphis, TN 38119

Phone: (800) 489-3863 or (901) 684-1697

Fax: (901) 684-1128

Email: [nftpr@aol.com](mailto:nftpr@aol.com)

Website: <http://www.transplants.org>

Gary McMahan, Executive Director

**Mission:** To provide financial and support assistance to transplant patients and their families.

**Materials:** NFT News.

**National High Blood Pressure Education Program**

NHLBI Health Information Center

P.O. Box 30105

Bethesda, MD 20824-0105

Phone: (301) 592-8573

Fax: (301) 592-8563

Website: <http://www.nhlbi.nih.gov/about/nhbpep/index.htm>

Edward J. Roccella, PhD, MPH, Coordinator

**Mission:** The National High Blood Pressure Education Program (NHBPEP), established in 1972, is a cooperative effort among professional and voluntary health agencies, State health departments, and many community groups. The NHBPEP is administered and coordinated by the National Heart, Lung, and Blood Institute of the National Institutes of Health. The goal of NHBPEP is to reduce death and disability related to high blood pressure through programs of professional, patient, and public education. To assist program participants in carrying out their diverse efforts, NHBPEP offers resources in several major areas: information collection and dissemination; public, patient and professional education; community program development; evaluation and data analysis; and technology transfer and electronic distribution.

**Materials:** Publications for patients and professionals.

### **National Hypertension Association, Inc.**

324 East 30th Street  
New York, NY 10016  
Phone: (800) 575-9355 or (212) 889-3557  
Fax: (212) 447-7032  
Website: <http://www.nathypertension.org>

**Mission:** The National Hypertension Association, Inc. (NHA) is a not-for-profit organization dedicated to combating the chronic health problem of high blood pressure (hypertension) by developing, directing, and implementing effective programs to promote research, educate the public, and ensure prompt detection and effective treatment of hypertension. The NHA was founded in 1977 by a group of scientists and laymen who were concerned with the health problems posed by hypertension in the U.S. The aim of the NHA is to conquer hypertension through a well-defined program of basic and clinical research, public and professional education, and detection.

**Materials:** 100 Questions and Answers about Hypertension.

### **National Institute of Diabetes and Digestive and Kidney Diseases**

National Institutes of Health  
Building 31, Room 9A04  
31 Center Drive, MSC 2560  
Bethesda, MD 20892-2560  
Website: <http://www.niddk.nih.gov>  
Dr. Allen Spiegel, Director

**Mission:** The National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) conducts and supports research on many of the most serious diseases affecting public health. NIDDK supports much of the clinical research on the diseases of internal medicine and related subspecialty fields as well as many basic science disciplines. The Institute's Division of Intramural Research encompasses the broad spectrum of metabolic diseases such as diabetes, inborn errors of metabolism, endocrine disorders, mineral metabolism, digestive diseases, nutrition, urology and renal disease, and hematology. Basic research studies include biochemistry, nutrition, pathology, histochemistry, chemistry, physical, chemical, and molecular biology, pharmacology, and toxicology. NIDDK extramural research is organized into divisions of program areas: Division of Diabetes, Endocrinology, and Metabolic Diseases; Division of Digestive Diseases and Nutrition; and Division of Kidney, Urologic, and Hematologic Diseases. The Division of Extramural Activities provides administrative support and overall coordination. A fifth division, the Division of Nutrition Research Coordination, coordinates Government nutrition research efforts. The Institute supports basic and clinical research through investigator-initiated grants, program project and center grants, and career development and training awards. The Institute also supports research and development projects and large-scale clinical trials through contracts.

**Materials:** Various materials for the general public, patients, and health professionals.

### **National Kidney and Urologic Diseases Information Clearinghouse**

3 Information Way  
Bethesda, MD 20892-3580  
Phone: (800) 891-5390 or (301) 654-4415  
Fax: (301) 907-8906  
Email: [nkudic@info.niddk.nih.gov](mailto:nkudic@info.niddk.nih.gov)  
Website: <http://www.niddk.nih.gov/health/kidney/nkudic.htm>

**Mission:** The National Kidney and Urologic Diseases Information Clearinghouse (NKUDIC) is a service of the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK). NIDDK is part of the National Institutes of Health under the U.S. Department of Health and Human Services. Established in 1987, the Clearinghouse provides information about diseases of the kidneys and urologic system to people with kidney and urologic disorders and to their families, health care professionals, and the public. NKUDIC answers inquiries, develops and distributes publications, and works closely with professional and patient organizations and Government agencies to coordinate resources about kidney and urologic diseases.

**Materials:** Various publications for patients and professionals.

### **National Kidney Disease Education Program (NKDEP)**

National Institute of Diabetes and Digestive and Kidney Diseases  
National Institutes of Health  
3 Kidney Information Way  
Bethesda, MD 20892  
Website: <http://www.nkdep.nih.gov>  
Dr. Thomas Hostetter, Director

**Mission:** The National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) of the National Institutes of Health has recently initiated the National Kidney Disease Education Program (NKDEP). This program will raise awareness about the seriousness of kidney disease, the importance of prevention and early diagnosis, and the importance of appropriate management of the disease and its complications.

### **National Kidney Foundation**

30 East 33rd Street, Suite 1100  
New York, NY 10016  
Phone: (800) 622-9010 or (212) 889-2210  
Fax: (212) 689-9261  
Email: [info@kidney.org](mailto:info@kidney.org)  
Website: <http://www.kidney.org>  
John Davies, Executive Director  
Diane Goetz, Director of Communications

**Mission:** To prevent kidney and urinary tract diseases, improve the health and well-being of individuals and families affected by these diseases, and increase the availability of all organs for transplantation.

**Materials:** Advances in Renal Replacement Therapy, American Journal of Kidney Diseases, CNSW Newsletter, CRN News and Briefs (newsletter), CNNT Newsletter, Family Focus (newsletter), Transplant Chronicles (newsletter), Journal of Renal Nutrition, Journal of Nephrology Social Work, For Those Who Give and Grieve (newsletter), and patient and public education materials.

**Other Services:** Council of Nephrology Nurses and Technicians (CNNT), Council of Nephrology Social Workers (CNSW), Council on Renal Nutrition (CRN), Council on Dialysis, Council on Transplantation, Council on Pediatric Nephrology/Urology, Council on Glomerulonephritis, Council on Polycystic Kidney Disease, National Donor Family Council, Patient & Family Council, transAction Council, Council on Diabetic Kidney Disease, Council on Hypertension.

**State Groups:** 52

### **NephCure Foundation**

505 East Huron Street, Suite 302

Ann Arbor, MI 48104

Phone: (866) 637-4287

Website: <http://www.nephcure.org>

Lissa Witcher, Executive Director

**Mission:** To serve as an active voice and support organization for families suffering from the increasing devastation of kidney filtration disease, and to fund researchers seeking the causes and cure.

### **Nephrogenic Diabetes Insipidus Foundation**

Main Street, P.O. Box 1390

Eastsound, WA 98245

Phone: (888) 376-6343

Fax: (888) 376-3842

Email: [info@ndif.org](mailto:info@ndif.org)

Website: <http://www.ndif.org>

**Mission:** To support education, research, treatment, and cure for nephrogenic diabetes insipidus (NDI). To create a communication channel to serve the entire NDI community: patients and their families, researchers, physicians, and other health care providers.

### **Nephrology Analytical Services**

914 South Eighth Street

Minneapolis, MN 55404-1204

Website: <http://www.nephrology.org>

**Mission:** To serve patients with end-stage renal disease (ESRD) by providing information to the dialysis community—physicians, researchers, clinicians, and patients themselves—that will ultimately improve patient outcomes and quality of life. To fulfill this mission, Nephrology Analytical Services has constructed a comprehensive and continually expanding database of claims, utilization, and provider data. This database enables analysis of clinical practices in the national ESRD population and evaluation of the impact of these practices on morbidity and survival. Part of the Minneapolis Medical Research Foundation.

### **North American Society for Dialysis and Transplantation**

4010 Bentley Drive  
Pearland, TX 77584  
Phone: (281) 997-1944  
Fax: (281) 997-0733  
Website: <http://www.nasdat.org>  
Laura Brazil, Executive Director

**Mission:** To disseminate current information about dialysis and transplantation; to provide an update for the status of the management of renal transplantation and its complications; and to provide an update on the mechanisms involved in the progression of renal disease.

### **North American Transplant Coordinators Organization**

P.O. Box 15384  
Lenexa, KS 66285-5384  
Phone: (913) 492-3600  
Fax: (913) 541-0156  
Email: [natco-info@goAMP.com](mailto:natco-info@goAMP.com)  
Website: <http://www.natcol.org>  
Deirdre Gish-Panjada, Executive Director

**Mission:** To support, develop, and advance the knowledge of its members and enhance the quality, effectiveness, and integrity of donation and transplantation.

**Materials:** In Touch (newsletter), Progress in Transplantation, and patient care brochures.

### **Office of Minority Health Research Coordination (OMHRC)**

National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK)  
National Institutes of Health (NIH)  
2 Democracy Plaza  
6707 Democracy Boulevard, Room 653  
Bethesda, MD 20892  
Phone: 301-594-1932  
Fax: 301-480-3510  
Website: <http://www.niddk.nih.gov/fund/divisions/omhrc/omhrcintro.htm>  
Dr. Lawrence Agodoa, Director

**Mission:** To address the burden of diseases and disorders that disproportionately impact the health of minority populations, the Director of the NIDDK created the NIDDK Office of Minority Health Research Coordination (OMHRC). The OMHRC will help implement the Institute's Strategic Plan for Health Disparities and build on the strong partnership with the National Center on Minority Health and Health Disparities at NIH. Among its many responsibilities and functions, the OMHRC, under the leadership of the Director identifies and advises the Director of the NIDDK of the disparities in disease areas of interest to the Institute.

Another important goal in lifting the disproportionate burden of disease is recruitment and training of minority biomedical investigators, who are currently in short supply. The OMHRC interacts with program staff in developing initiatives to train new and young investigators who are underrepresented in biomedical research. OMHRC tracks and evaluates the Institute's progress in training underrepresented racial and ethnic minorities in biomedical research.

### **Oxalosis and Hyperoxaluria Foundation**

5718 Holly Hills  
St. Louis, MO 63109  
Phone: (888) 721-2432, pin# 5392, or (314) 351-2177  
Fax: (314) 481-6368  
Email: [execdirector@ohf.org](mailto:execdirector@ohf.org)  
Website: <http://www.ohf.org>  
Lauri Royer, Executive Director

**Mission:** To inform the public, especially patients, parents, families, physicians, and medical professionals, about hyperoxaluria and the related conditions (i.e., oxalosis and calcium-oxalate kidney stones); to provide a support network for those affected by hyperoxaluria; and to support and encourage research to find a cure for hyperoxaluria.

**Materials:** "in touch" (newsletter), public education materials.

### **Polycystic Kidney Disease Foundation**

4901 Main Street, Suite 200  
Kansas City, MO 64112-2634  
Phone: (800) PKD-CURE or (816) 931-2600  
Fax: (816) 931-8655  
Email: [pkdcure@pkdcure.org](mailto:pkdcure@pkdcure.org)  
Website: <http://www.pkdcure.org>  
Dan Larson, President and CEO  
Dale Culver, Vice President

**Mission:** To promote programs of research to determine the cause, improve clinical treatments, and discover a cure for polycystic kidney disease (PKD).

**Materials:** PKD Patient's Manual; Q & A on PKD; The Family and ADPKD; PKD Progress (patient newsletter/5 per year); Your Child, Your Family and Autosomal Recessive PKD; Health Tips for Living with PKD; audio tapes from 12th Annual Conference on PKD; PKD Info Packet (sent free to anywhere in the world).

### **Renal Physicians Association (RPA)**

4701 Randolph Road, Suite 102  
Rockville, MD 20852  
Phone: (301) 468-3515  
Fax: (301) 468-3511  
Email: [rpa@renalmd.org](mailto:rpa@renalmd.org)  
Website: <http://www.renalmd.org>  
Chaim Charyton, M.D., President  
Dale Singer, MHA, Executive Director

**Mission:** To ensure optimal care under the highest standards of medical practice for patients with renal disease and related disorders, to act as a national representative for physicians engaged in the study and management of patients with renal disease and related disorders, and to serve as a major resource for the development of national health policy concerning renal disease.

**Materials:** RPA News, bimonthly, available at no cost to members; clinical practice guideline on adequacy of hemodialysis; ESRD in the Age of Managed Care: A Primer on Capitation; and other position papers and guidelines.

### **Transplant Recipients International Organization**

2117 L Street N.W., Suite 353  
Washington, DC 20037-1524  
Phone: (800) TRIO-386 or (202) 293-0989  
Fax: (415) 239-8727  
Email: [TRIOIntl@aol.com](mailto:TRIOIntl@aol.com) or [trio@mindspring.com](mailto:trio@mindspring.com)  
Website: <http://www.trioweb.org>  
Lisa Kory, Executive Director

**Mission:** Transplant Recipients International Organization (TRIO) is an independent, not-for-profit, international organization committed to improving the quality of life of transplant candidates, recipients, donors, and their families. Through the TRIO headquarters and a network of chapters, TRIO serves its members in the areas of awareness, support, education, and advocacy.

**Materials:** Lifelines (bimonthly), Membership Update (once a month for members).

### **The Transplantation Society**

Central Business Office  
205 Viger Avenue West, Suite 201  
Montreal, QC H2Z 1G2  
CANADA  
Phone: (514) 874-1998  
Fax: (514) 874-1580  
Email: [info@transplantation-soc.org](mailto:info@transplantation-soc.org)  
Website: <http://www.transplantation-soc.org>  
Carl Groth, President

**Mission:** To further knowledge in transplantation biology and medicine.

**Materials:** Transplantation, Transplantation Proceedings, Transplant Infectious Disease, Graft, Transplant Immunology, Xenotransplantation.

### **United Network for Organ Sharing**

1100 Boulders Parkway, Suite 500  
P.O. Box 13770  
Richmond, VA 23225  
Phone: (804) 330-8500  
Website: <http://www.unos.org>  
Walter Graham, Executive Director

**Mission:** To administer the national organ procurement and transplantation network and the national organ transplantation scientific registry under contracts with the Health Resources and Services Administration, a division of the U.S. Department of Health and Human Services. The purpose of the United Network for Organ Sharing (UNOS) is to promote, facilitate, and scientifically advance organ procurement and transplantation and to administer an equitable organ allocation for the entire Nation. The UNOS Scientific Registry is a comprehensive organ transplantation data system enabling scientists and other interested individuals to access information for all liver, heart, heart-lung, pancreas, kidney, and small bowel donors and recipients in the United States since October 1, 1987.

**Materials:** UNOS Update and educational materials.

**Local Groups:** 11 regions.

### **United States Renal Data System**

USRDS Coordinating Center  
914 South 8th Street, Suite D-206  
Minneapolis, MN 55404  
Phone: (888) 99-USRDS or (612) 347-7776  
Fax: (612) 347-5878  
Email: [usrds@usrds.org](mailto:usrds@usrds.org)  
Website: <http://www usrds.org>  
Allan J. Collins, MD, FACP, Coordinating Center Director

**Mission:** The United States Renal Data System (USRDS) is a national data system that collects, analyzes, and distributes information about end-stage renal disease in the United States. The USRDS is funded directly by the National Institute of Diabetes and Digestive and Kidney Diseases in conjunction with the Center for Medicare & Medicaid Services. The USRDS Coordinating Center is operated under a contract with the Minneapolis Medical Research Foundation.